

PEER REVIEW HISTORY

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Multidisciplinary teams caring for people with variations of sex characteristics: Myth or reality?
AUTHORS	Gramc, Martin Streuli, Jürg de Clercq, Eva

VERSION 1 – REVIEW

REVIEWER	Reviewer name: Dr. Alison Berner Institution and Country: Tavistock and Portman NHS Foundation Trust, Gender Identity Clinic Competing interests: None
REVIEW RETURNED	13-Aug-2021

GENERAL COMMENTS	<p>Many thanks to the authors for this scoping review which highlights the lack of variability in practice with regard to an MDT approach to caring for those with VSC and their families.</p> <p>I think that this is an important topic to be highlighted in the journal and one which I hope could stimulate further primary research and policy review.</p> <p>I have some minor revisions which I think would clarify and enhance the article prior to any publication.</p> <p>Page 6, line 10 – I think the different types of MDT collaboration will not be wholly familiar to the readership and the authors should expand on these and their importance here. Did the Chicago consensus specify which MDT approach would be most appropriate? Are there standards for defining these types?</p> <p>Page 7 line 10 – Conference abstract were excluded but it would be useful to know if many would have met the search criteria as I can imagine that this topic is more likely to be covered at a conference rather than as a full research paper. Whilst I agree that a conference abstract is unlikely to provide sufficient depth to be included, it may help in drawing conclusions to understand what is being presented on the topic.</p> <p>Page 7, line 14 – The authors mention that some search terms were not included as they did not yield additional results. Could the authors clarify whether this was the case with “variations of sex characteristics” as this is the current preferred term both within the community as I understand, and also within the paper? If this was not checked then it would constitute a major revision as any search results for this term should be included.</p> <p>Page 9, line 10 – ?Typo – ‘unfied’ should read ‘unified’?</p> <p>Page 9, line 10 – Typo – ‘elligible’ should read ‘eligible’.</p> <p>Page 9, line 37 – Grammar – ‘was published’ should read ‘were published’.</p>
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	<p>Page 13, line 5 – ‘variations of sex characteristics’ used in full where abbreviation could now be used. Check for this in the rest of the paper.</p> <p>Page 14, lines 22,34 – Typo – ‘MDTS’ should read ‘MDTs’.</p> <p>Page 14, lines 36-38 – The authors state “One fourth of the papers stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process.” Could this statement be clarified? Do the authors mean that the need for confidentiality of patient info means that team members cannot collaborate? Or that the sharing of information is in fact a barrier to collaboration somehow? This is not clear to me and seems an important point to explain. Similarly in line 38, what ‘difficulties of diagnosis’ are being referred to? Understanding the nuances of these barriers will add to the paper.</p> <p>Page 16, line 19 – The phrase “alleviating emotional distress of parents facing the fact that they have a child with VSC” could be perhaps be put in quotation marks or rephrased as it could itself be deemed to stigmatise VSC I think.</p> <p>Page 16, lines 21-24. This section becomes a bit repetitive talking about most of the papers focussing on infants and none on adults. Could this be summarised a little more neatly?</p> <p>Page 17, Limitations – This section could be expanded to discuss the implications of what might be missed by excluding conference abstracts and grey literature. Also, if more empirical research is being proposed, then this could be discussed in more detail, perhaps providing a checklist of what such studies should cover in light of what has been found to be absent in this review.</p>
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VERSION 1 – AUTHOR RESPONSE

We appreciate the opportunity to resubmit our manuscript for consideration for publication in BMJ Paediatrics Open. We thank the reviewer for their thoughtful feedback and suggestions for revisions. The reviewer’s original comments are followed by a response in bold addressing the concern and changes made. All changes are highlighted in yellow in the manuscript for easy detection.

This is a fascinating paper which uncovers a range of really interesting aspects.

Reading this struck me how inconsistent medical professionals are with the phrase 'MDT'. Within cancer, it can often be used as a shorthand for the scheduled, regular, diagnostic tumour board or psychosocial professionals review meetings. It's clear it can be read as understanding shared decision making throughout a management path too.

Response: Thank you so much for your interest in this topic and helpful feedback below.

As a scoping review, this article expands a little beyond the usual scope. The degree of synthesis, without clear use of any appraisal/bias/assessment instrument on the included articles I find difficult. Scoping reviews typically assess the areas covered and comment on the zones rather than the detail of content:

<https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/s12874-018-0611-x>

(For example, the first line of the conclusion in the abstract indicates a 'finding about MDTs' rather than a description of the literature discovered.)

Response: We thank the reviewer with the suggestion and we have clearly indicated the use of instrument in the text where it was needed.

As such, the authors should consider if they wish to report this as a scoping review, or undertake a more complex appraisal/assessment element, including the consideration of the 'truth' within the narrow beams of illumination provided by these few studies, and present their synthesis this way.

Response: We would prefer to keep it as a scoping review as we aim to map the available literature on multidisciplinary teams working with intersex and identify knowledge gaps. We would also prefer to keep it as scoping review as the appraisal of methods etc. would be very time consuming.

Page 6, line 10 – I think the different types of MDT collaboration will not be wholly family to the readership and the authors should expand on these and there importance here. Did the Chicago consensus specify which MDT approach would be most appropriate? Are there standards for defining these types?

Response: We thank the reviewer for the suggestion and we agree with them that that the description of these different types of MDT is quite vague and that we too have asked ourselves the following question: what might be the purpose of listing and describing these various forms of MDT without indicating which one is the most appropriate. We added the following clarification in the text:

The Chicago consensus doesnot specify which MDT would be the most appropriate. However the 2016 update defines types of collaboration in detail. In multidisciplinary teams two or more team members work simultaneously but separately; interdisciplinary teams involve the joint work of professionals from different disciplines sharing knowledge and skills to address a common problem and in transdisciplinary teams various disciplines are brought together to create new ways of solving problems and share resposibility of care (Lee et al. 2016). Although Lee and colleagues (Lee et al. 2016) explain the differences between these types of teams, they do not give any practical indications on how to set up such teams, nor do they explain which type of team is more suitable in which kind of context.

Page 7 line 10 – Conference abstract were excluded but it would be useful to know if many would have met the search criteria as I can imagine that this topic is more likely to be covered at a conference rather than as a full research paper. Whilst I agree that a conference abstract is unlikely to provide sufficient depth to be included, it may help in drawing conclusions to understand what is being presented on the topic.

Response: Conference abstracts were not included as they often do not provide more detailed account of what was said in the presentation and thus give no substantial information. Since we excluded conference abstracts from the very start of our extraction process it would be impossible for us to trace back the number of eligible conference abstracts.

Page 7, line 14 – The authors mention that some search terms were not included as they did not yield additional results. Could the authors clarify whether this was the case with “variations of sex characteristics” as this is the current preferred term both within the community as I understand, and also within the paper? If this was not checked then it would constitute a major revision as any search results for this term should be included.

Response: We thank the reviewer for their important comment. Variations of sex characteristics was originally included as a potential search term but not included in the final search query as it did not give additional results, showing that the term is not (yet) adopted by the medical literature but mostly used by support groups

We apologize for the following language errors and typos. We have made the necessary changes.

Page 9, line 10 – ?Typo – 'unfied' should read 'unified'?

Response: Yes, it should read 'unified'.

Page 9, line 10 – Typo – 'elligible' should read 'eligible'.

Response:Yes, it should read 'eligible'.

Page 9, line 37 – Grammar – ‘was published’ should read ‘were published’.
Response: Yes, it should read ‘were published’.

Page 13, line 5 – ‘variations of sex characteristics’ used in full where abbreviation could now be used.
Check for this in the rest of the paper.
Response: Yes, I checked and changed the abbreviation on page 12 (line 3) and 13 (line 5)

Page 14, lines 22,34 – Typo – ‘MDTS’ should read ‘MDTs’.
Response: Yes, it should read MDTs.

Page 14, lines 36-38 – The authors state “One fourth of the papers stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process.”
Could this statement be clarified? Do the authors mean that the need for confidentiality of patient info means that team members cannot collaborate? Or that the sharing of information is in fact a barrier to collaboration somehow? This is not clear to me and seems an important point to explain.

Response: Thank you for this suggestion, we have clarified the paragraph as follows:
One fourth of the papers^{9,12,21} stressed the absence of confidentiality between team members, patients and parents as a barrier to collaboration process because sharing information can be distressing to parents to the point where they cannot participate in the shared decision making process.

Similarly in line 38, what ‘difficulties of diagnosis’ are being referred to?

Response: We thank the reviewer for the important remark. Difficulties of diagnosis refer to the time of diagnosis and the precise determination of VSC.

Page 16, line 19 – The phrase “alleviating emotional distress of parents facing the fact that they have a child with VSC” could be perhaps be put in quotation marks or rephrased as it could itself be deemed to stigmatise VSC I think.

Response: Thank you for this suggestion. We have put the phrase in quotation marks: “alleviating emotional distress of parents facing the fact that they have a child with VSC”.

Page 16, lines 21-24. This section becomes a bit repetitive talking about most of the papers focussing on infants and none on adults. Could this be summarised a little more neatly?

Response: We thank the reviewer for this suggestion. We have summarized the section as followed, see page 21-24.

This might be since the majority of papers focused on infants and children, however these studies failed to address the role and implementation of shared decision making for them. The studies also did not refer to care of adults and transition of care from adolescence to adulthood.

Page 17, Limitations – This section could be expanded to discuss the implications of what might be missed by excluding conference abstracts and grey literature. Also, if more empirical research is being proposed, then this could be discussed in more detail, perhaps providing a checklist of what such studies should cover in light of what has been found to be absent in this review.

Response: We thank the reviewer for this suggestion and have made the necessary changes. The text now reads:

The scoping review explored the existing literature on MDTs examining the collaboration processes and ethical frameworks. Some relevant studies might have been overlooked due to exclusion/inclusion criteria, e. g. conference abstracts and grey literature might have provided information from patients on the MDTs. Nevertheless, our review provides an overview of the existing literature on collaboration of MDT caring for people with VSC and provides important directions for further research that will hopefully lead to better care of people with VSC. Therefore we propose the following suggestions for future

research: investigating the role of the health care professionals in the teams in the decision making process; examining the nature of relationship between patients and MDTs; examining the lack of care for adults and transition; more research on how MDTs can actually work together; researching new models of collaboration within the MDTs and how they relate to ethical dilemmas working with people with VSC: informed consent vs. growing mental capabilities of children and their rights to participate in their treatment.

Response: Dear editors, I would like to add that in the first submission I forgot to add dr. Eva de Clercq as the third author of the paper in the submission application. This mistake has been corrected. I apologise for the mistake.